Scottish Partnership for Palliative Care (SPPC) response to the consultation on a proposal for a Bill to give people of all ages living with terminal illness and residing in Scotland a legal right to palliative care

About SPPC

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement. SPPC recently won a Public Service Award for its portfolio of work.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all IJBs, all Local authorities, the hospices, a range of professional associations, many national charities and social care providers.

How this response was developed

A draft of this response was circulated for comment to SPPC member organisations and stakeholders. The draft was also discussed at several stakeholder meetings. Input was also gained from Marie Curie and CHAS roundtable discussions.

Aim and approach

1. **Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?**

☒ Strongly agree
☐ Partially agree
☐ Neutral (neither support nor oppose)
☐ Partially disagree
☐ Fully disagree
☐ Unsure

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

SPPC strongly supports incorporating a right to palliative care into Scots law. We believe that over time such a law will improve the experiences of people living with serious illness, dying and bereavement in Scotland, through an improvement in the care they receive.

Importantly, a legal right to palliative care could provide greater clarity and assurance to the public about what care and support they can expect when living with serious illness, dying and bereavement.

Everyone dies and experiences bereavement – they are the most universal and profound experiences. Over 60,000 people die each year in Scotland and up to 90% of those who die could benefit from palliative care. Demand for palliative care is expected to grow 20% by 2040. On any day of the year 1 in 3 acute hospital beds in Scotland are occupied by people in their last year of life. Most people in care homes for older people are in the last 18 months of life.

Most people die in old age. However, the numbers of children (using the term here to include babies and young people) in Scotland with palliative care needs is going up. There are there are more than 16,700 children (aged 0-21) across Scotland who may die from a life-shortening condition. Although many of these children are stable at present, and some may make a complete recovery from illness, nearly 6,000 will need hospital care in a given year. And about three children die from a life-shortening condition every week in Scotland. More children than ever before are living with significant medical complexity. Throughout the process of developing legislation and guidance it is vital to actively consider how provisions may impact provision of palliative care for children. In some case general provisions and guidance may be adequate to cover all ages. However, it may often be necessary to make distinct provision for children and their

families, since their circumstances and experiences are very different to that of adults. We say more about these differences below.

The scale and importance of living with serious illness, dying and bereavement have not been reflected in an adequate, sustained institutional focus and priority on improving palliative care and support. Scotland doesn't gather systematic data on people's experiences and outcomes at the end of life, despite the recommendation of the Health and Sport Committee Inquiry into Palliative Care (2015). There are no national standards of care for people approaching the end of life. Improvement of palliative care has been the subject of successive Scottish Government strategies since 2000. However, despite improvements there remain deficiencies in the reliability of basic care, and the public face uncertainty about what care and support they can rely on towards the end of life.

Legislating for a right to palliative care is not a panacea or a short term fix. However, a legal right to palliative care could place a clear duty on public bodies to improve palliative care (we say more about how this could be implemented in practice under Q4 below).

The Public Bodies (Joint Working) (Scotland) Act 2014 which underpins health and social care integration makes it legally *possible* for organisations to do much of what is required to improve palliative care. However, actual improvements have over the past decade have been disappointing because there is no specific onus on IJBs to act, and SG reports limitations on its ability to direct integration bodies to take action. In relation to palliative and end of life care there are no specific duties to:

- Assess the needs of the local population
- To measure experiences and outcomes
- To plan for improvement
- To tackle inequalities
- To establish effective joint agency working
- To report on progress

The legislation should aim to deliver improvement on those issues which matter most to people who are living with serious illness, dying and bereavement. People usually value:

Autonomy

People generally value a sense of being in control, yet ill-health often throws people into situations no-one would choose. The options available to an individual may be limited for various reasons, but it is important that people are supported to retain the autonomy to choose from the options that are available for as long as possible.

The Chance to Explore Personal Preferences

Planning ahead for deteriorating health increases the likelihood that a person will receive the kind of care they would like. Therefore, efforts to encourage this kind of future care planning and to promote more cultural openness about death are welcome. Not everyone will *want* to plan ahead or talk about death, but everyone should have *opportunities* to do so, accompanied by the recognition that people's needs and wishes can change over time and that plans should be reviewed and updated. It is important that every individual has the opportunity to tell their own story, and that others listen to find out what matters to them and what support they might need.

Honesty and Openness

While remaining sensitive to an individual's situation and sensitivities, healthcare and social care professionals need to be open and honest with the person about their expectations for that person's health. This includes what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided. The desire to shield people from unwelcome information is understandable. Learning that someone will not get better, or that the ideal support services are not available, or that the end of life is close, will likely always be difficult. Yet, without honest information, individuals and families are ill-equipped to make decisions or plan ahead. Thinking about serious illness and death can be difficult for both professionals and for the public but recognising shared mortality and common humanity is where good palliative and end of life care builds from.

At a more detailed level the right to palliative care should include:

- rapid relief from distressing symptoms wherever possible (whether physical, emotional, psychological, spiritual)
- reliable and consistent access to support and advice from healthcare and social care professionals who are compassionate, knowledgeable and competent
- information about what is happening, what is likely to happen next, the uncertainties that might be involved, to inform people's thinking about what their priorities may be
- empathy and support in adjusting to coping with uncertainty and deteriorating health
- support to get the most out of whatever time is left with the people they care about
- time, space and support to discover and maintain a sense of meaning, purpose and spiritual wellbeing in new and changing circumstances
- support for psychological wellbeing
- access to short breaks/respite and other support for the people they care about who are caring for them
- support with financial, legal and other practical issues, including the 'little' things that can make a big difference, like mowing the lawn, or taking the dog for a walk

- access to more specialised support if bereavement (or anticipatory grief) becomes harder to cope with and someone needs extra help in addition to the understanding and support from family, friends, colleagues and community

Some thoughts on the importance and complexity of *where* someone is cared for and dies:

People often express a wish to be cared for and to die at home. For many people their home is somewhere familiar, where loved ones can be to hand, and where important words and moments can be shared in privacy. Home can be a personal, intimate and individual space steeped in meaning.

However, often people's needs and priorities change as the realities and uncertainties of serious illness become manifest. Someone might wish to avoid feeling as though they are 'burdening' family members; to be sure of quick access to rapid treatment or to feel secure with experienced staff close by.

Sometimes there may be trade-offs to consider and choices to be made between the place someone would ideally want to be and other things that are important to them.

Care homes, hospitals, hospices and individual homes are all places where people can live and receive good care when they are seriously ill or dying. For some people at the end of life "home" may be a prison or a homeless hostel and good care should be available there too, despite evident challenges. Each setting has an important role to play as complementary parts of a single system.

It is therefore important that, wherever someone is living, efforts are made to enable them to experience as much of the 'essence of home' as possible. For many people, that is about having privacy, individuality and space for intimacy and important relationships.

2. **What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?**

   Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

What is palliative care?

SPPC recognises that the term "palliative care" is not well understood. It is also used to mean different things by different people in different contexts. This is a challenge for legislation.

Though more specific definitions can be helpful, one way of thinking about "palliative care" is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Therefore, in Scotland, much of the care that people receive when their health is deteriorating could be termed general palliative care, being provided by health and social care staff to people living in the community, in care homes and in hospitals. It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home or in a medical ward, ICU or neonatal ward, whether they are a baby or a centenarian. Palliative care can and should be delivered alongside active treatment where that is appropriate.

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Often people with complex needs are support by generalists with the support and advice of generalists.

Palliative care includes, but is not exclusively about, *end of life care*. End of life care is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Defining when would someone have a right to palliative care

There is existing statutory guidance used to determine whether a person has a "terminal illness" for the purpose of accessing Scottish social security benefits (*Updated Guidance on the Implementation of Benefits Assessment under Special Rules in Scotland (BASRiS) Guidance and form for Terminal Illness, for Disability Benefits devolved to Scotland*. Chief Medical Officer December 2023). This guidance states:

> *"To meet the definition the individual should have an illness:*
>
> *a) that is advanced and progressive or with risk of sudden death, AND;*

b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;

c) that is leading to an increased need for additional care and support."

All people meeting these criteria should have a right to palliative care. However, SPPC believes that this definition would exclude some people, and is not fully compatible with the WHO definition which states that palliative care may be of benefit from the point of diagnosis (whereas this BASRiS eligibility is restricted to those with advanced disease). To bridge this gap, and to provide a more inclusive but still workable approach, SPPC suggests that:

- people should have a right to palliative care when they meet the BASRiS conditions for eligibility
- people should also be able to request and receive an assessment of their palliative care needs from the point of diagnosis, and have a right to palliative care where needs are then identified.

How to define palliative care for the purposes of legislation

SPPC accepts the WHO definition as a useful and authoritative articulation of the aims and scope of palliative care for adults. It could be a useful definition for legislative purposes. However, we believe that the WHO definition would need to be supplemented by more specific guidance. We believe the guidance should include a statement of national standards which help to illustrate what palliative care means *for the purposes of this Bill*. These standards should complement and not duplicate existing health and social care standards. These standards should be based around what matters to people who are seriously ill, dying or bereaved (see response to Q1). The standards would also be an opportunity to make some important aspects of palliative care more explicit, for example social care, bereavement support and support for carers. This specific guidance would have 3 purposes. Firstly to inform the work of service providers in delivering the right to palliative care. Secondly to provide the basis of monitoring and reporting of the realisation of the right to palliative care. Thirdly the guidance would form the basis of clear information for the public about their entitlement to palliative care.

We believe that this structure of high-level definition with more detailed guidance and standards would be appropriate for any legislative route.

Palliative care for children has significant differences to that for adults. We say more about this in question 3. Children's Hospices Across Scotland provide more detailed and expert views in their response to the consultation. It is vital that specific guidance supporting the Bill encompasses the particular and very varied needs of babies, children and young people, and of children transitioning to adult services. Existing work

could be adapted to inform guidance. For example *A Framework for the Delivery of Palliative Care for Children and Young People* (Scottish Children and Young People's Palliative Care Executive Group 2012) , set out a range of outcomes and objectives for service providers including Health Boards, Social Work, Education, CHAS and other voluntary organisations - taking into consideration the age, geographical and social needs of their particular population of children and young people.

Palliative care and the National Care Service (NCS) Bill

In addition to being a broad "framework" or "enabling" Bill the NCS bill as it currently stands makes provision for some specific rights. "Section 38 Rights to breaks for carers" legislates to place duties on public bodies with the intention of improving access to respite care. Section 40 creates a right to visits to or by care home residents. The NCS Bill could therefore reasonably be further amended to create a right to palliative care. In addition, palliative and end of life could be specifically mentioned in the National Care Service Principles (Section 1). Detail about palliative care could be included in the NCS Charter (Section 11). Duties to plan, commission and improve palliative care could be included in Sections 6-9 and associated guidance.

Palliative Care and Scottish Human Rights Legislation

The forthcoming Scottish Human Rights Bill will incorporate several international treaties into Scots law, making it easier for people to access their rights (and to create clear duties for public bodies to realise those rights). The International Covenant on Economic, Social and Cultural Rights (ICESCR) will be incorporated and this includes Article 12 "*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*." The Bill will contain interpretative provisions and these could include clear and specific references to a right palliative care. Additionally a right to palliative care could be included in the sections about "Minimum Core Obligations".

The principle of the right to palliative care aligns well with the United Nations Convention on the Rights of the Child (UNCRC) which has already been incorporated into Scottish law. Children under the age of 18 already have a range of rights that are, broadly speaking, pertinent to a right to palliative care. These include the right to: my best interests being considered (article 3); life (article 6); to be listened to (article 12); to join in (article 15); information (article 17); protection from harm (article 19); reach full potential as a disabled child (article 23); be as healthy as possible (article 24); an education (article 28); rest, relaxation and play (article 3). The UNCRC is a "floor" and not a ceiling of rights compliance. It sets minimum standards beyond which duty bearers can and should strive. A right to palliative care could be seen as a natural extension to the clauses set out above, for some of Scotland's most vulnerable babies, children and young people.

Significant work has been undertaken in Scotland to develop approaches to realising the rights in the Scottish Human Rights Bill and the UNCRC. This work can inform how a right to palliative care can be realised, including issues such as supporting people to access their rights, and judicial and non-judicial routes to redress where rights are denied.

The importance of all influences on people's experiences of living with serious illness dying and bereavement

In our response to this consultation we focus on the care and support which people receive from services – both specialist palliative care services and general palliative care provided across the health and social care system. However, it is important to recognise that people's experiences of living with serious illness, dying and bereavement are only partly determined by the services they do or don't receive.

'Public Health Palliative Care' (PHPC) aims to understand and influence the social and structural factors that affect people's experiences of death, dying, loss and care. It is based on a belief that death, dying, loss and care are experiences shaped by all aspects of society including culture, economics, politics, schools, workplaces, communities and the media. Therefore, though clinical and therapeutic interventions provided by formal health and social care services are recognised as essential in improving experiences, a PHPC approach looks further upstream and across the whole population, to how factors such as education, financial hardship, health/death literacy, community resources and social support, can impact on the experiences someone has around deteriorating health, dying and bereavement.

PHPC is a broad field that encompasses work to effect change in a range of areas. For example, how can public policies make better provision for people who are caring, dying or grieving? How can cultures and opportunities be created so that matters relating to serious illness, dying and bereavement can be discussed and acted upon? How can communities of all kinds be strengthened with knowledge, skills, networks, resources, confidence and opportunities to support each other? What information and education will allow people to develop their personal skills and knowledge of these issues? What inequalities exist in people's experiences and how can these be addressed?

PHPC is particularly associated with approaches such as community development, health promotion and public education. Prominent initiatives include death cafes and compassionate communities work, but PHPC encompasses much more than this including: death education courses; public awareness campaigns; funeral poverty initiatives; lobbying for policy changes; encouraging future care planning; death education and bereavement support in schools; compassionate workplace projects

and more. The variety of approaches and areas of activity where change is needed means that many different institutions and communities have roles to play in PHPC.

Because of the breadth and diversity of domains relevant to public health palliative care we believe it would be difficult to legislate comprehensively in this area. However, as an alternative, we believe that an Act creating a legal right to palliative care should place a duty on government and public bodies to consider, assess and take into account the potential impacts (positive and negative) of any new policy on people approaching the end of life.

3. **Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).**

   What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

   ☐ Strongly agree
   ☐ Partially agree
   ☐ Neutral (neither support nor oppose)
   ☐ Partially disagree
   ☐ Fully disagree
   ☐ Unsure

   Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

(The question as worded above can't be answered using the Likert scale).

There is evidence that many different circumstances and individual characteristics disadvantage people and lead to worse experiences and outcomes at the end of life. It is important to remember that people can be disadvantaged in multiple ways at the same time. Whilst an improved understanding of the needs and experiences of specific groups is important, each person is an individual and within groups there will be heterogeneity.

There is evidence of worse experiences/outcomes (in some or different respects) for the following groups: older people; black and ethnic minority groups; homeless people; prisoners; forced migrants; people with learning disabilities; people living in areas of socioeconomic deprivation; people experiencing financial hardship; LGBTQ+ people;

gypsy, traveller and Roma people; people with some specific diagnoses or classes of diagnosis; women; people in remote and rural areas; people with severe/enduring mental health issues.

Inequalities towards the end of life generally reflect patterns of inequality and discrimination within wider society. Societal approaches which tackle inequality, poverty and discrimination are fundamental to improving experiences and outcomes at the end of life. There is now good evidence for how governments can address poverty-related health inequalities by addressing the wider social determinants of health. Social movements, properly enforced equalities legislation and society-wide campaigns are the basis for challenging discrimination and stigma at societal level.

Measures which aim to make general services more accessible and person-centred will help to address inequalities in palliative and end of life care – for example work currently being done under the banner of health literacy . However, there are also specific actions within the sphere of palliative and end of life care which can contribute to addressing inequalities.

The implementation of a right to palliative care would represent an opportunity to address current inequities at the end of life. Those bodies responsible for the planning, delivery and improvement of palliative care should prioritise specific action to improve outcomes for disadvantaged groups. This should include: identification of the needs, preferences and barriers experienced by specific groups; service redesign informed by the experiences of specific groups; staff training in the needs of different groups; ongoing monitoring of the outcomes and experiences of specific groups.

Palliative Care for Babies, Children and Young People

The needs babies, children and young people, and their families are very specific and in many ways very different to that of adults. Children's Hospices Across Scotland (CHAS) has recently engaged with children and families to understand their experiences and priorities. They report that there are three critical states on their journey:

> ***"Learning your child is seriously ill and may die young***
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> *Learning your child is seriously ill and may die young is heartbreaking. Families tell us they need more support at the beginning of their journey. For most, this shocking news means entering a world they know nothing of, while feeling the loss of the life they were expecting with their child. Families need more emotional, clinical, and practical help at this early stage, when their lives change enormously. This includes advice and support around financial wellbeing, fun activities, medical advice and social work.*
>
> ***Living well***

Caring for a seriously unwell child is exhausting for the whole family. The pressure of round-the-clock care puts a strain on family life. Parents should be parents, not just carers, and children should be able to be children and have fun, no matter how short their life is. And siblings of seriously ill children often describe how hard their childhood is. The whole family – including parents and siblings – need help to live well with complexity, worry and uncertainty. This includes helping children be included and to have fun, creating precious memories that will last a lifetime.

Dying well and Bereavement

The death of a child is overwhelming, distressing and catastrophic. Just as every child is unique, so is every death. Families told us that a meaningful goodbye is important and that choice in place of death and good planning can support families in their immediate grief, and beyond. More families are choosing home as place of death, which often requires specialist care and support 24 hours a day from CHAS and a range of partners.

Palliative care for children is different from adult palliative care in several important ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood or young adulthood.
- Many of the illnesses are familial, so there may be more than one affected child in the family.
- Parents bear a heavy responsibility for personal and nursing care and siblings are especially vulnerable.
- A characteristic of childhood is continuing physiological, emotional and cognitive development. Children's palliative care providers need to understand and be responsive to the impact of a child's physiological development on handling of medications as well as each child's changing levels of communication and ability to comprehend their illness, treatments and prognosis.
- Provision of play for all children is essential and education is a legal entitlement.

Statutory guidance should be created that specifies the important particulars in relation to paediatric palliative care.

4. **What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented.**

   Please explain the reasons for your response.

Challenges to improving palliative care

The organisation and delivery of adult palliative care is complex and fragmented. Organisations involved in providing palliative care include general practice, community nursing, community pharmacies, care homes, care at home services, hospices, NHS 24, NHS specialist palliative care units, Scottish Ambulance Service, and both acute and community hospitals. In addition to the NHS substantial parts of palliative care are delivered by the Third Sector, the Independent Sector and local authorities.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities. Palliative and end of life care has a key role to play in addressing the quality, safety and resource challenges facing NHS Scotland and Integration Authorities, and contributing to national priorities and outcomes. High quality palliative care – delivered in a range of settings - can reduce inappropriate hospital admissions, reduce overtreatment, facilitate discharge, support people and their families in the community, promote person-centred care and shared decision making, and support wellbeing during whatever time remains.

This context of multiple delivery agencies, parallel planning processes, and complex lines of accountability has tended to lead to a lack of strategic attention on care during this phase of life. Individual and organisational discomfort in contemplating mortality (or an internalised belief that because death is inevitable there is nothing which can be done to improve associated experiences) has sometimes compounded this lack of specific focus. Despite being a huge part of what the health and social care system delivers each day palliative and end of life care is often surprisingly invisible in polices, plans, strategies and measurement of outcomes. In addition to the complex institutional landscape described above palliative care spans all demographics, transcends specific conditions and settings, and has outcomes which are complex to measure. In addition, since most palliative care takes place in general settings, it can be hard to identify a baseline for a significant proportion of the resource use.

The organisation and delivery of palliative care for children is also complex and fragmented, but structures, processes and challenges differ.

Approaches to implementing a right to palliative care

Legislation is not a magic wand which can change things overnight. There will remain a need for strategies, plans, improvement programmes, training and education of staff,

investment, research and *sustained institutional focus and effort over time*. SPPC's report *Every Story's Ending* sets out a comprehensive analysis and set of proposal to improve people's experiences of living with serious illness, dying and bereavement in Scotland.

SPPC supports an approach of "progressive realisation" which recognises that some aspects of desired change will take longer than others. SPPC also believes that there are aspects of palliative care which should be minimum core obligations which should be implemented reliably with minimal delay. This sort of phased approach could be considered alongside the development of national standards for palliative care (see Q2). Standards could usefully be structured in tiers. A baseline tier could define minimum core obligations (minimum service standards). A second level could define higher standards which might not be achievable everywhere at the outset but which would provide a basis for future planning and improvement.

Delivering a right to palliative care

A legal right to palliative care would signal that the care of people in their last years, months, week and days of life is a national priority. This is a key condition for change and improvement. Government policy and leadership can also support change.

At local level to deliver a right to palliative care there is a need for:

- a visible locus of senior leadership and accountability for the improvement of palliative and end of life care
- interagency partnerships charged with improving care. These partnerships will need representation from across the health and social care system, and need time to develop relationships, trust and shared ownership of improvement
- a systematic and effective approach to identifying people with high and increasing needs who are at risk of dying
- routinization of future care planning
- a digital platform which can share and update people's future care plans across settings
- investment in rapid response community supports for people and their carers
- shared accountability for outcomes which are measured, understood, reported and published. Critically we need to refocus resources on outcomes which represent value – to the system, to society and to individual people.

At local level the legal responsibility for palliative care should lie with a local statutory organisation which has the power and influence to convene the necessary interagency

partnership. The partnership should have sufficiently senior sponsorship to enable the alignment of resources across settings and between agencies.

The Bill should require annual reporting by Scottish Ministers on progress towards making the right to palliative care a reality.

An important aspect of delivering a right to palliative care will be adequate public education and information. People in Scotland will need to know more than currently about what palliative care is, how it may benefit them or people they know, and how they can go about receiving it when they need it.

Data for service planning, improvement and assurance

In recent years there have been improvements in the data available to describe the patterns of service use towards the end of life (descriptive analytics). There is a need to develop better data to enable predictive analytics (what the future might hold for services and populations), prescriptive analytics (options for future direction) and evaluative analytics (did it make a difference and was it worth it). A notable and vitally important gap to fill at an early stage is the systematic national gathering of data on people's experiences of care and outcomes towards the end of life – there is no perfect mechanisms to achieve this but there are a range of options and several comparable jurisdictions have made good progress on this.

A suite of indicators linked to national standards should be developed.

5. **Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?**

   Please explain the reasons for your response.

SPPC recognises the financial pressures face within health and social care services. Services also face increased demands due to an aging population. However, although people tend to use a bit more healthcare as they age the major increase in healthcare use occurs in the last year of life. A right to palliative care which ensures a greater system-wide focus on this phase of life has the potential to drive a better use of limited resources. Specifically most of the increased expenditure in the last year of life relates to hospital admissions. Whilst some of these admissions are necessary and provide valuable investigations and treatments not possible elsewhere, many people spend time in hospital at the end of life undergoing treatment which has little or no benefit, or waiting to be discharged, when they would often prefer to be elsewhere. Too many admissions are the result of health and social care supports in the community being

unable to respond to crisis or deterioration. Acute hospital is often the default and that is often bad for people and a sub-optimal use of public finances.

The Highland End of Life Care Together partnership is taking a "value-based" approach to improving end of life care. The aim is to align the use of resources in a way which focuses on the outcomes that people value most, whilst also delivering value to the system (more efficient resource use) and to wider society (for example by reducing trauma and complex grief which can result from bad end of life experiences).

Much provision of specialist palliative care and end of life care in Scotland is provided by the 3rd sector. There is a need to reform funding mechanisms to ensure that these services have secure and sustainable finances.

There is real potential for win-wins: better use of resources and better outcomes which reflect what people really value towards the end of life.

References are available on request for the key facts and figures in this report.

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This response is on behalf of an organisation, Scottish Partnership for Palliative Care.
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